Cancer Care Nova Scotia

Being Informed – Getting Involved

Report on the
Cancer Patient Family Network Roundtable
Thursday May 30, 2002

Strachan•Tomlinson
June 12, 2002

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Preface

"This was a valuable experience for me. I hope I can pass it on and make some small difference in quality cancer care."

The Cancer Patient Family Network (CPFN) Roundtable provided an opportunity for people who have been involved with the Nova Scotia cancer care system to discuss what they have learned from their experiences and contribute those insights to the further development of the CPFN. This report summarizes participants' conclusions and recommendations for the next steps in shaping a dynamic CPFN 2002 – 2005.

Evaluations from the Roundtable indicated that participants appreciated the opportunity to provide input and discuss ways to ensure that the next few years are a productive growth experience for the CPFN. The level of commitment to developing a strong advocacy network was clear: participants also emphasized the importance of the CPFN having a unique mandate, structure and functions that did not duplicate existing services but enables collaboration with others to advance the quality of cancer care in the province. In this vein, not all the suggestions included in the report fall within the mandate of CCNS; we welcome the opportunity to pass on, or work with others, on ideas and initiatives that belong to partners who have related commitments to quality cancer care for Nova Scotians.

Much was learned at this Roundtable – about local area services, about the needs of individuals and communities, about where we should go from here. This report is intended as a forward thinking guide to action over the next few years. It is not intended to provide a verbatim account of discussions, but to note conclusions and recommendations focused on positive, system-based changes.

We at Cancer Care Nova Scotia welcome these recommendations and will use this report as a guide to future action. We will also keep Roundtable participants informed about our progress and how they can participate in next steps.

Dr. Andrew Padmos, BA, MD, FRCPC
Commissioner, ***Cancer Care Nova Scotia***
Head, Cancer Care Program, QEII HSC
Associate Dean, Cancer Programs, Dalhousie University

Emmie Luther-Hiltz
Coordinator, CPFN
Cancer Care Nova Scotia

Cancer Care Nova Scotia

Report: Round Table on the Cancer Patient Family Network May 30, 2002

Executive Summary

The purpose of this Roundtable was to further establish a Cancer Patient and Family Network (CPFN) for Nova Scotia. Objectives were to:

- bring together stakeholders from across Nova Scotia who share an interest in developing a system where health professionals and cancer patients/survivors and family members can work together to improve the cancer care system
- learn about consumer involvement in health care quality issues
- consult with interested parties on a common vision for the Network
- develop recommendations for action in two areas:
  - building the Network, and
  - developing an initial agenda for the Network.

The Roundtable brought together over 90 participants representing patients and survivors and their families, health care providers, and other stakeholders with diverse experience and expertise and a strong commitment to develop a patient family network in Nova Scotia.

A. The CPFN Vision

Participants provided rich, incisive commentary on a vision for the CPFN. Suggestions for alternate names focused on expanded involvement, e.g., the Cancer Family Network, the Cancer Community Advocacy Network. Key points from participant feedback included:

- clearly define the Network's role
- emphasize community involvement
- avoid duplicating the work of other organizations or groups
- include accountability in the vision statement.

B. Challenges

Prior to the Roundtable, the following two types of challenges for the CPFN were identified based on responses to the pre-Roundtable questionnaire.

i. Strategies for Network Development
   - Becoming Known
   - Recruitment/Involvement

ii. Building a Network Agenda
   - Access
   - Service Needs
   - Communication
   - Information.

Participants worked in small groups to identify key areas and develop recommendations for each challenge. Most recommendations resulting from discussions applied to both rural and urban situations so this distinction is not noted in the report. Over 60 recommendations were developed for the six challenges in areas such as information dissemination, transportation, resources, membership and collaboration.

C. Structure

When asked to give their "best advice" regarding a possible structure for CPFN, participants recommended that the purpose, focus and target membership of the Network should be further clarified and defined before developing a structure. Other recommendations addressed issues of local empowerment and community involvement and the need to start small, with a very tight focus. Avoiding duplication of existing services was a key concern.

Conclusion

The CPFN Roundtable was an important opportunity for stakeholders in the cancer care system to meet and provide feedback from their perspective on Network requirements. Passionate and productive discussions ensured that the Roundtable objectives were met. Key outcomes included recommendations related to the CPFN vision, challenges and structure. Evaluations demonstrated that the consultation was well received by participants, who look forward to contributing to the achievement of an effective patient family network in Nova Scotia.

Introduction

"Roundtables are a hallmark of the way we conduct our business. They are one way we can discuss important issues with and learn from you, our customers – cancer patients, your families, friends, volunteers, doctors, other health professionals and all Nova Scotians. By working together we will find solutions to meet our collective needs."

The purpose of this Roundtable was to further establish a Cancer Patient and Family Network (CPFN) for Nova Scotia. Objectives were to:

- bring together stakeholders from across Nova Scotia who share an interest in developing a system where health professionals and cancer patients/survivors and family members can work together to improve the cancer care system
- learn about consumer involvement in health care quality issues
- consult with interested parties on a common vision for the Network
- develop recommendations for action in two areas:
  - building the Network, and
  - developing an initial agenda for the Network.

This report summarizes deliberations at the Roundtable. Detailed reports of discussions have been provided to ***Cancer Care Nova Scotia*** under separate cover.

Opening Remarks

Participants were welcomed by Mr. Jack Keith, Chair, ***Cancer Care Nova Scotia*** (***CCNS***) Board of Directors, who emphasized the ***CCNS*** Board's belief in the importance of involving cancer patients and their families to improve the cancer system in Nova Scotia. He noted that the Roundtable was an opportunity for stakeholders to work together and learn from each other to strengthen the cancer system and create another excellent "made in Nova Scotia" solution for cancer patients and their families.

Dr. Andrew Padmos, Commissioner, ***CCNS***, provided an overview of the role of ***CCNS*** in the cancer care system (see Appendix #2 for more information related to this overview). He reminded participants that the CPFN is a new concept: the creation of an organization that primarily serves the interests of those who use the system. He encouraged participants to push the envelope – ***CCNS*** is not about setting limitations; it is open to all suggestions. In closing, Dr. Padmos affirmed that he was excited to reach this point, and that this Roundtable is the beginning of an exciting venture. He hoped that this workshop would provide an opportunity to harness the energy and passion of participants towards improving the cancer care system.

Participants

Participants were diverse in experience, expertise and geographical location. Their reasons for attending the Roundtable were also varied, e.g., to

- contribute to and accomplish the dream of developing a patient family network
- seek and gather information on the CPFN and the Nova Scotia cancer care system in general
- ensure that the voices and experiences of patient/survivors and their families are taken into account
- represent members of the community who may not always be heard or who may require special attention, e.g., pediatrics, seniors, First Nations
- network and learn more about how to form support groups
- help develop linkages, close gaps and eliminate duplication
- pursue a professional interest in helping cancer patients.

Being Informed

Two presentations provided background and context to the day's discussions: Emmie Luther-Hiltz, Co-ordinator of the CPFN, described the origin and current situation of the CPFN in her presentation, "CPFN Past and Present". Dorothy Strachan, workshop facilitator, outlined current initiatives around the world in her presentation, "Why CPFN? Consumer Involvement in Quality Health Care".

Presentation slides are included in Appendix #2.

The CPFN Vision

Participants reviewed a definition of a vision and discussed the strengths and weaknesses of the following draft CPFN vision statement:

> *In 2005, the Nova Scotia Cancer Patient Family Network will be a dynamic virtual community of folks who are informed about and involved in the provincial cancer care system. The CPFN will be the primary mechanism for cancer patients, survivors, family members and volunteers to work with others in improving and strengthening the Nova Scotia cancer care system.*

Strengths of the draft vision and suggestions for improvement are summarized below. Please note differences of opinion among participants, e.g., with respect to wording.[1]

Strengths

- The wording is appealing, e.g., dynamic, improve and strengthen, primary mechanism, virtual community
- The approach is forward-thinking, realistic and do-able; it gives direction for a mission statement.
- The perspective is inclusive, grassroots driven and community-based, e.g., it talks about consumers throughout the entire cancer journey; family is broadly defined; responsibility for building the network is at the community level.
- The tone is firm and strong. It emphasizes the importance and influence of a collective voice for patients/survivors in decision making and policy development on key issues such as resources for transportation, drugs.
- It's positive and gives a sense of hope, that something significant will be done based on this beginning.
- The emphasis is on consumers, volunteers and family members who are better informed and therefore better able to participate in system reform.
- The statement uses language that is plain, clear and understandable: it spells out clearly who the network is for and who is involved.
- The Network could provide a peer review system to make recommendations for action.
- This vision supports information sharing across organizations, meetings and systems.

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[1] This section provides a summary of key comments; detailed suggestions provided at the Roundtable have been submitted to the CPFN Coordinator for consideration.

Suggestions for Improvement

- Be clear about the role of the CPFN in providing a unified voice for patients in discussion and decision making.
- Be more specific, e.g., mention information sharing; environmental and nutritional issues, the larger health system; spell out what you mean by "work with others".
- Change the name to include Atlantic CPFN.
- Check to ensure that the vision is realistic: can we do this in this time period? Make sure that the vision doesn't pressure over-extended volunteers for more participation.
- Clarify that the Network isn't a support group and ensure that the vision doesn't lead to confusion between the Network and other roles (e.g., Patient Navigator) and services (e.g., support).
- Clarify where health care professionals fit in. Who are "others"?

  "I want to know what to do to help make it easier for my patients to deal with the confusion of treatment and care for their cancer."
- Develop a brief, simple and catchy slogan that is easy to remember and encourages buy-in.
- Distinguish the CPFN vision from that of the Canadian Cancer Society and other groups like it.
- Emphasize that 2005 is the first part of the vision and there are other parts to come.
- Ensure that the vision includes the complete segment, i.e., the "24,000" possible members in Nova Scotia.
- Recognize the complex reality of our society, e.g., literacy needs, multi-culturalism, situation of aboriginal peoples.
- Re-think some of the wording, e.g.,
  - change *cancer patients, survivors, family members and volunteers* to *people who care*, or *people living with cancer*
  - consider using the phrase *people affected by cancer*
  - don't use words such as *virtual* or *folks*
  - replace *mechanism* with *voice*; replace *primary mechanism* with specific names
  - use *community* instead of *family*
  - what do words like *involved* and *clarity* mean?
- Strengthen the vision statement by including an accountability statement in it that focuses on building trust and mutual respect.

- Re-visit the name: some parts of it work well (e.g., it's inclusive) but it's hard to remember. Options for names include:
  - Cancer Community Advocacy Network – C-CAN
  - Cancer Community Network – CCN
  - Cancer Family Network – CFN
  - Cancer Network: Patients, Survivors, Family and Supporters – CN-SFS
  - Cancer Patient Family/Survivor Network – CPFSN
  - Cancer Patient/Survivor Family Network – CPSFN
  - Patient/Survivor or Cancer Family Network. – PSFN or CFN.

Suggested Vision Statements

1. The Network will provide a formal opportunity to be informed (disease specific and/or information on community support), engaged in policy development and decision making and valued as equal partners in the quest to improve and strengthen the Nova Scotia cancer system.
2. In 2005, the Nova Scotia Cancer Community Network will be a dynamic community of people who are informed about and involved in the cancer care system. The CCN will be a facilitator for people who live with cancer, (family members, supporters, volunteers, and care providers) to understand, improve, and live well within the cancer care system.
3. By 2005, the Nova Scotia Cancer Patient Network will be a dynamic community that is informed about and involved in the provincial cancer care system. The network will be the mechanism for cancer patients, survivors, family members and volunteers to communicate about the cancer system and provide the opportunity to work towards improving and strengthening the Nova Scotia cancer care system.
4. The Nova Scotia Cancer Family Network will become a dynamic virtual community of people who are informed about and involved, by 2005, in the provincial cancer care system. The CFN will be a mechanism for cancer patients, survivors, family members and volunteers to work with others in improving and strengthening the Nova Scotia cancer care system.
5. In 2005, CPSFN will provide the mechanism through which patients and families of patients living with cancer can access resources, affect change and enhance their lives and the lives of others through a network of communication and commitment.
6. In 2005, the Nova Scotia Family Network will be a dynamic, informed community of individuals involved in the provincial cancer care system. The CFN will be the primary mechanism of cancer patients, survivors, family members and volunteers to work with others to improve and strengthen the Nova Scotia cancer care system.

Getting Involved: Rural and Urban Perspectives

"There is an incredible need for the network to have a clear focus that can lead to an early win."

Prior to the Roundtable, the following challenges for the CPFN were identified based on responses to the pre-Roundtable questionnaire. The challenges are grouped into two types:

A. Strategies for Network Development

- Becoming Known
- Recruitment/Involvement

B. Building a Network Agenda

- Access
- Service Needs
- Communication
- Information.

Participants worked in small rural or urban-specific groups to identify key areas and develop recommendations for each challenge. Most recommendations resulting from discussions applied to both rural and urban situations so this distinction is not noted in the report.

A. Strategies for Network Development

Challenge #1: Becoming Known

"We've all come a long way in the last ten years in regard to patient feedback and kindness to each other."

1.1 Information Dissemination

We recommend that the CPFN:

- develop a 1-800 single access line
- include an information piece as part of mail-outs by other organizations, e.g., Nova Scotia Medical Society, Registered Nurses Association of Nova Scotia, provincial government
- include information with pathology reports, e.g., Pink Rose & Reef Knot kits
- link its web site through the Capital District Health Authority to Community Access Program sites
- make information available in various situations, e.g., at the point of diagnosis, anywhere people wait, through word-of-mouth, particularly in rural areas[2], through access to technology, e.g., libraries with computer terminals
- speak to health care professionals
- take into account all means of information delivery, not just technology based, e.g., technology solutions may not work in rural areas.

1.2 Liaison

We recommend that the CPFN:

- develop a liaison network that will represent each geographical area, e.g., local representation
- focus on local contacts to build community liaison
- work with the Community Access Program at Dartmouth General .

1.3 CPFN Profile

We recommend that the CPFN:

- develop high quality, focused, credible information packages for a variety of situations and distribution methods
- look for opportunities for guest speakers at service clubs
- not only convey its presence but clarify its purpose and goals, e.g., "why are you here and what can you do for us".

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[2] Consider benefits and drawbacks of sharing information versus confidentiality issues.

Challenge #2: Recruitment/Involvement

"The process of introducing the network and increasing participation can be assisted by building on the existing services and groups already established in rural communities."

2.1 Collaboration

We recommend that the CPFN:

- clarify its vision, goals and objectives and where it overlaps with other cancer related organizations, i.e., find ways to collaborate with other organizations in the community so that all are sustainable
- ensure that all geographical areas in each district participate equally and provide financial resources
- ensure that education and outreach become a major focus of recruitment that is sensitive with respect to culture, age and literacy
- facilitate the exploration of local solutions to address problems, issues or gaps, e.g., bring together groups such as service clubs that may have solutions or resources to share
- invite participation from representatives of all forms of cancer disease and offer participants clearly defined goals when working on behalf of the network.

2.2 Focus

We recommend that the CPFN:

- retain a professional group to develop a clear profile for the network, e.g., logo, spokesperson, etc.
- speak with one voice to bring common issues to government and appropriate agencies.

2.3 Finding Members

We recommend that the CPFN:

- focus on accessing different age groups, e.g., through other organizations and support groups and through using the Internet to access younger people
- make use of existing linkages to recruit new members, e.g., Patient Navigators, Nurse Practitioner pilot project, the NS Tobacco strategy, the Canadian Cancer Society, and other existing groups
- participate in discussions at locally based roundtables or "kitchen table" events in diverse communities to identify individuals who want to be further involved
- place a standing recruitment piece in the CPFN newsletter encouraging new members to join and requesting existing members to update their information regularly
- use appropriate and relevant strategies and information to access diverse populations with varied needs.

2.4 Representation

We recommend that the CPFN:

- be aware of contacts in all cultures (e.g., in First Nations, the Health Director) through development of a contact list that identifies ethno-cultural representatives
- ensure appropriate representation of children of parents with cancer, e.g., reach the children through the patients, then have a Patient Navigator revisit the situation after a period of time.

B. Building a Network Agenda

Challenge #3: Access

"The money should follow the patient."

3.1 Transportation

We recommend that the CPFN:

- advocate with Halifax Regional Municipality, Capital District Health Authority, Department of Health and other new partners for improved transportation strategies and resources
- develop a comprehensive living arrangement directory for rural patients who need to travel several hours for treatment
- do an inventory of available resources for transportation and inform patients and health professionals
- in cases where patients must travel long distances to access medical service, provide services (post chemotherapy, etc.) in the facilities where the treatment is delivered. Treatment should be available to the patient as close to home as possible
- keep the transportation issue on the agenda
- look at the simple, obvious things, e.g., there is no bus stop at the Dickson Centre.

3.2 Literacy

We recommend that the CPFN:

- provide assistance to patients with literacy problems through family networks and support groups, and through partnerships with literacy groups
- recognize that access to information on the Internet is not a high priority in terms of literacy.

3.3 Resources

We recommend that the CPFN:

- advocate for more resources and funding for acute care facilities to address long waiting lists for service
- ensure that low income patients, or patients with other financial issues have access to drugs, medical supplies and ambulance services.

3.4 Information

We recommend that the CPFN:

- become part of multiple dissemination strategies
- educate and empower patients
- link with the patient orientation package already available
- partner with others to educate health professionals through Continuing Medical Education.

Challenge #4: Service Needs

"There is not enough money to address all needs. CPFN can offer the perspective that will result in allocation of human and financial resources that will focus on the needs of the patients."

4.1 Information Requirements

We recommend that the CPFN:

- define its role, particularly in ensuring the provision of relevant, usable information tailored to individual needs, e.g.,
  - Is the purpose of the Network to assess information for patients and families? Be a place where issues can be identified? Act as a lobby group for issues that have been identified?
  - How can the Network effect change and serve communities so that patient families can have a voice?
  - Is the Network involved in assisting with the development of clinical guidelines where patients and families would be called upon for their input?
  - How would patients and families be represented?
  - How does the network know which issues belong to the Network and which to other bodies? For example, would the Network address issues related to continuity of care? cost of medication? home care services? wait times for tests and results?
- get clearly focused on activities; the Network can't be all things to all people.

Challenge #5: Communication

"A newly diagnosed cancer patient is the loneliest person in our society. This continues well into the treatment phase. Care and reduction of anxiety is an essential, if not the primary, part of treatment."

5.1 Advocacy

We recommend that the CPFN:

- be an advocate for identified problems affecting patients and be empowered to participate in the solution
- enable patients to discuss options with their family physicians by ensuring that the physicians are informed of the results of consultations with the patient's specialist
- identify a medical ombudsperson to assist cancer patients and their families in dealing with the medical system.

5.2 Communications

We recommend that the CPFN:

- develop a CCNS-approved web site with appropriate links
- form a volunteer communications committee to respond to questions from patients (e.g., 1-800 number) with resources provided to this committee by CCNS
- work with others to mobilize the Patient Navigator system in District 3, e.g., provide a patient navigator and appropriate information at time of diagnosis; identify approved resources within the District.

Challenge #6: Information

"I've learned a lot about cancer as a survivor of 16 years, but I struggled for a long time without information or support."

6.1 Information

We recommend that the CPFN:

- compile and provide a list of locally available resources across the province, including support networks, transportation, day care facilities, and contact numbers for patients and families living with cancer. Disseminate the information in appropriate ways, including in-person communicators, Internet, written materials for families and health care providers and through partnership with local service groups
- develop local champions (with loud voices) to represent the network to local communities and provide training for support group coordinators
- ensure the availability of French language information
- focus on reaching the medical community for support and referrals
- give us a voice and an ear in government to point out what works, what doesn't work, and what is needed
- help enhance the effectiveness of the communication skills of health care providers by helping them to address personal issues related to death and terminal illness
- provide personal delivery of information as much as possible (particularly in rural areas) and community education to groups through speakers
- roll out the Patient Navigation system across the province as soon as possible and enhance the role of the Patient Navigator to complement the purpose of the CPFN
- supply information in a form that suits individuals at all educational levels
- together with other organizations, explore opportunities to eliminate duplication and enhance the efficiency and effectiveness of overall information delivery through a review and assessment of existing strategies, e.g.,
    - assess each individual's needs and learning styles (e.g., computer, telephone, face-to-face) at the start of their cancer journey
    - ensure timely delivery of information on diagnosis (e.g., through same-day faxing or a 1-800 number), wait times, and quality of care at different sites
    - identify service duplication and gaps within existing systems
    - identify alternate and complementary treatment options.

6.2 Quality Assurance

We recommend that the CPFN:

- develop and implement best practice guidelines related to:
  - diagnosis, to ensure that all options are explained and available to all patients without the barriers of finances, distance and intimidation
  - treatment wait times for each diagnosis
- ensure that out-of-province referrals are to competent physicians and that patient information travels back to Nova Scotia
- ensure that patient rights are understood through informing/educating doctors and patients about information sharing and shared decision making
- include Cumberland County in access to information
- monitor and evaluate quality of service and the quality of information available to patients
- provide tools to make informed, wise health care decisions
- work with patients to educate about and monitor implementation of best practice guidelines for cancer care.

Structure

Participants were asked to give their "best advice" regarding a possible structure for CPFN. Their conclusions are summarized below.

It is premature to develop a structure, e.g.,

- form follows function: review, clarify and define the purpose and focus of the Network; when we know where we want to go, we can build the structure
- take a look at what already exists and what each individual community needs before developing the structure
- we need more information to guide this discussion and help us make decisions.

The structure should:

- address the need for local involvement and empowerment through local and district health boards
- be free-flowing and amoeba-like – keep it small and simple, e.g., an umbrella organization with smaller District groups
- grow as it is needed; we have to be patient and understanding
- include a mechanism to support the Coordinator
- not duplicate systems, programs and structures that are already out there.

- ***CCNS*** could act as a coordinating body to develop standards and provide administrative organization but with local delivery and champions, e.g., ACT.
- Continuous quality evaluation and quality information are essential.
- Organizations are only as strong as the people at the top. We need to ensure strong, professional representation at senior levels.
- Start small and focus on one thing at a time - achieve an early success and the rest will follow.

Discussion

- A clear focus for the CPFN will enable early wins that demonstrate its potential: in this way, the Network can build ownership through small successes.
- Confidentiality is an issue with important implications for the Network in relation to coordination and membership, e.g., Physicians have to recommend that patients join the CPFN; they can't pass information directly to the CPFN.
- Given that the ***CCNS*** Board reports directly to the Department of Health, it is well placed to influence the government. The CPFN will be the foundation of the accountability process.
- Provision of care is the direct responsibility of the District Health Authority or relevant health care institution. ***CCNS*** is connected directly to the cancer service at QEII so that the QEII cannot function independently of cancer programs. The ***CCNS*** Commissioner is also the Director of Cancer Services at QEII. Corporate responsibility rests with the legislated authority of DHAs. This process was established to ensure credibility in the cancer care system.
- The CPFN target audience and membership needs to be clearly defined. Taken at its broadest, it could include 78% or more of the population of Nova Scotia.
- The Network could be similar to a corporation, with members acting as shareholders consulted through ad hoc arrangements, annual meetings, and local communication vehicles.
- The role of ombudsperson is important but may not be a principal role for the CPFN, e.g., it may be more useful to educate patients regarding ombudspeople and what to expect from them.
- There are structures in the province that already relate in some ways to the CPFN vision. How will the CPFN relate to and support established district cancer programs? Perhaps a separate structure isn't needed.
- We need to be respectful of the fact that patient/survivors, families and other possible members have different capacities at different times to contribute to the network.
- What is the potential role and involvement of Roundtable participants in relation to the future structure?

Closing Remarks

In her closing remarks, Dr. Carol Smillie, Co-Chair, ***CCNS*** Board CPFN Steering Committee thanked participants and the Roundtable Working Committee for their hard work in making this Roundtable so dynamic and informative. She assured participants that they had been listened to, that their input would help provide clarity to the organization of the CPFN and its priorities – and that their "contagious caring" had made a powerful contribution to the health of Nova Scotians.

Appendix #1: Key Terms

Roundtable

An assembly of people around a table for discussion at a conference at which all participants are accorded equal status.

The round table at which the legendary British King Arthur and his chosen knights sat so that none should have precedence.

A branch of an international charitable association founded in 1927, which holds discussions, debates, etc., and undertakes community service.

Consensus

Most dictionary definitions equate "consensus" with "unanimity", but at this workshop, the word will have its more popular meaning "substantial agreement".

We will measure the degree of consensus that has been achieved by asking participants to express one of the following positions:

- **I agree** with the proposal;
- **I can live with** the proposal;
- **I disagree**, or **remain undecided**.

Collaboration[3]

Is a process through which parties who see different aspects of a problem can constructively explore their differences and search for solutions that go beyond their own limited visions of what is possible. Collaboration is based on the simple adage that two heads are better than one and that one by itself is not good enough.

Not all collaborations lead to agreements for action, but when agreements are reached, they are arrived at by consensus. Consensus is achieved when each one of the stakeholders agrees they can live with a proposed solution, even though it may not be their most preferred solution.

Collaboration as it is defined here should be distinguished from the terms cooperation and coordination as used by Mulford and Rogers (1982). **Cooperation** is "characterized by informal trade-offs and by attempts to establish reciprocity in the absence of rules" (Mulford and Rogers, 1982, p.13). **Coordination** refers to formal institutionalized relationships among existing networks or organizations.

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[3] Barbara Gray. *Collaborating: Finding Common Ground for Multiparty Problems.* Jossey-Bass Publishers, London, 1989, 5.

Dynamics of Collaboration

Collaboration involves a process of joint problem solving and/or decision making among key stakeholders of a problem domain about the future of that domain. Five features are critical to the process:

(1) the stakeholders are interdependent

(2) solutions emerge by dealing constructively with differences

(3) joint ownership of decisions is involved

(4) stakeholders assume collective responsibility for the future direction of the domain, and

(5) collaboration is an emergent process.

Nature of Collaborative Problems

There is no shortage of problems for which collaboration offers a decided advantage over other methods of problem solving and/or decision making. The characteristics of these problems can be described generally as follows:

- The problems are ill defined, or there is disagreement about how they should be defined.
- Several stakeholders have a vested interest in the problems and are interdependent.
- These stakeholders are not necessarily identified a priori or organized in any systematic way.
- There may be a disparity of power and/or resources for dealing with the problems among the stakeholders.
- Stakeholders may have different levels of expertise and different access to information about the problems.
- The problems are often characterized by technical complexity and scientific uncertainty.
- Differing perspectives on the problems often lead to adversarial relationships among the stakeholders.
- Incremental or unilateral efforts to deal with the problems typically produce less than satisfactory solutions.
- Existing processes for addressing the problems have proved insufficient and may even exacerbate them.

Vision

- is a statement describing the preferred future for the CPFN
- looks three years ahead, occasionally longer
- provides a realistic stretch for the CPFN
- enrols others through its focus and appeal.

Appendix #2: Presentations

1) *CCNS* Overview

Dr. Andrew Padmos, Commissioner, *CCNS*

People have said they do not understand what *Cancer Care Nova Scotia* does...

Who We Are

- Created in 1998
- Program of the Nova Scotia Department of Health
- Mandate to:
  - Coordinate
  - Strengthen
  - Evaluate.

What Does This Mean?

We work with:

- district health administrators
- health professionals
- community based organizations
- patients and families (CPFN).

Partnerships and Products

- Cancer Site Teams and treatment guidelines
- Community based medical oncology clinics
- Patient Navigation program
- Patient education resources.

In Progress

- District Cancer Programs
- Provincial cancer drug therapy program
- Research program development
- Health professional education
- Public health promotion.

What We Do Not Do

We do not:

- Deliver patient care
- Operate support groups
- Conduct cancer research
- Raise funds

Core Principles

- Stakeholder involvement
- Strength through collaboration not ownership

2) Cancer Patient Family Network: Past and Present

Emmie Luther-Hiltz, Coordinator, CPFN

"Experience is not what happens to you; it's what you do with what happens to you."

Aldous Huxley

Coordinator of CPFN - June 2001

- Dedicated to development of cancer patient/survivor/family community
- Establishing contact and communication with cancer patients and families
- Meeting with health professionals about the role that patients/families can play

What I've learned

- There is no other formal CPF Network in Canada!
- Patients and their families = knowledge, experience, passion, commitment
- Health professionals recognize and welcome patients' input

First Steps

- Visiting communities to meet with individuals, groups
- Asking patients/families to self-identify themselves by joining CPFN
- Establish regular communication, i.e. newsletters

Increasing Membership

- Cancer Centres provide CPFN information/membership sheet to newly diagnosed cancer patients
- CPFN info included in Living Well With Cancer displays around the Province
- Discussed by Patient Navigators in the communities

What do Members receive?

- Receive regular updates about cancer care programs, treatment, research
- Learn about opportunities for involvement
- Be asked for your opinion on how we can change the cancer system (to make it more patient-centred).

Accountability and Action

- Establish a reporting structure from patients/families to the ***CCNS*** Board and on to the Minister of Health.
- Provide a mechanism to engage patients and their families in the development and improvement of cancer system services.

The Role of *CCNS*

- Taking responsibility to develop the cancer patient/survivor/family community through the Network
- Coordinating, partnering, encouraging, collaborating, listening, leading, organizing, supporting, learning

Partnership Initiatives

- National Cancer Survivors Day - ***CCNS***, CCS, Caring for Cancer Patients
- Nova Scotia Breast Cancer Network - ***CCNS***, BCANS, CBCF, Health Canada
- Patient Resource Room - NSCC

Current Membership

- 180 members representing all areas of Nova Scotia
- Disseminate information by mail
- Network Members serve on District Cancer Committees

Membership in Future

- Potential for thousands of people in Nova Scotia (24,000 Nova Scotians living with a diagnosis of cancer)
- Electronic Network
- Annual Regional and Provincial Meetings

"Nothing great was ever achieved without enthusiasm."
Ralph Waldo Emerson

Resource Contact

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Coordinator, CPFN
Cancer Care Nova Scotia
Phone (902)473-2637
Toll free 1-866-599-2267
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Web site: www.cancercare.ns.ca

3) Why CPFN? Consumer Involvement in Quality Health Care

Dorothy Strachan, Facilitator

Quality Health Care System

A high quality health care system is:

- client-centred
- integrated
- responsive and cost-effective
- addresses quality issues across the continuum of care (promotion, prevention, treatment) as well as across care settings.

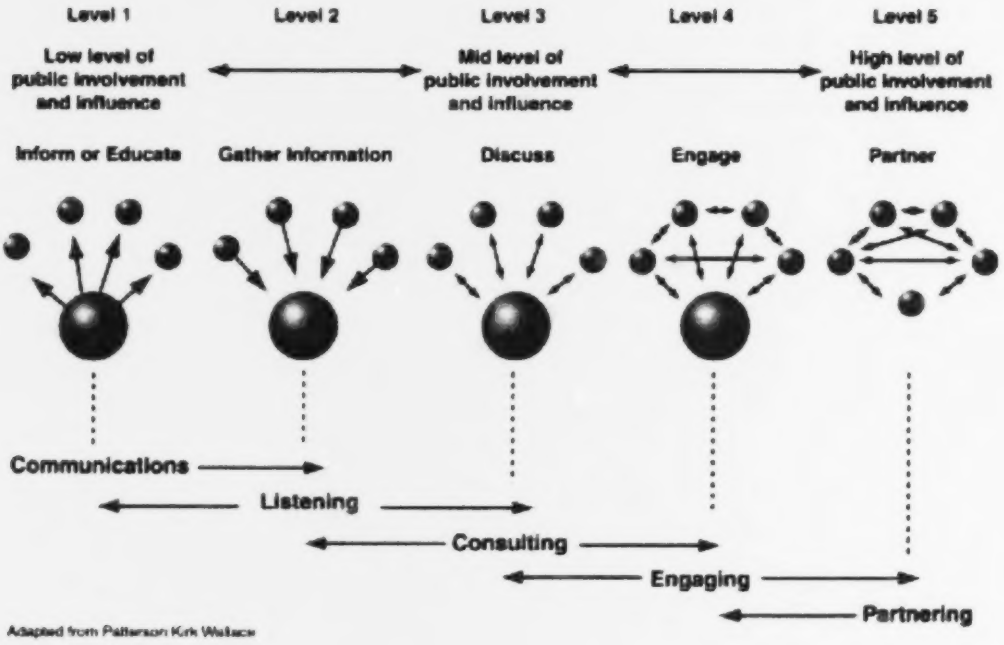
Fundamental concepts include:

- safety
- effectiveness
- appropriateness
- consumer participation
- access
- efficiency.

Consumer Involvement

- The goal of consumer involvement is to improve the quality of how policies and decisions are made.
- Provides new opportunities to bring interested parties together as civic-minded individuals concerned about health issues.
- Builds on, complements and generally moves beyond information distribution and consultation practices.
- Involves individual consumers, not just representatives of associations and other interest groups, in policy formulation, priority setting and program delivery
- Is a key component of "governance" of the health care system.

Consumer Involvement Curriculum



Consumer Involvement in Quality Health Care: International Activities

- NICE: Citizen Council Of United Kingdom
- Health Care Quality Improvement in New Zealand
- Australian Council for Safety and Quality in Health Care
- Improving Health Care Quality in the U.S.
- Consumers' Health Forum of Australia
- Advocating for Health Care Quality in the U.S.

Why CPFN?

- Consumer involvement in the cancer care system is an essential element in building quality health care for all.

Appendix #3: Resources

Atlantic Provinces Pediatric Hematology Oncology Network (APPHON)

Mission

The Mission of APPHON is to facilitate access for Atlantic province children and youth to comprehensive, current, evidence-based hematologic/oncologic treatment delivered as close to home as safely feasible.

The specific aims for APPHON:

- To enable access to and delivery of integrated, current, comprehensive, evidence-based investigation, treatment, monitoring and follow-up for Atlantic provinces children and youth with cancer or serious hematologic disorder;
- To facilitate shared care throughout the Atlantic provinces by influencing health care delivery systems; to facilitate the provision of family- centered, evidence-based, cost-effective care delivered through a collaborative practice;
- For health professionals caring for children and youth with cancer of serious hematologic disorder, to have access to a network of health professionals interested in pediatric hematology/ oncology health care;
- To develop Atlantic province-wide standards, guidelines and care maps for pediatric hematology/ oncology health care;
- For health professionals caring for children and youth with cancer or serious hematologic disorders, to obtain ongoing professional education to maintain currency in the field and the opportunity to participate in determining the design of local clinical research protocols;
- To advocate for necessary resources and evaluate, monitor and improve the system for pediatric hematology/ oncology health care delivery within the Atlantic provinces.

Membership

- Any Atlantic province organization involved in the delivery of health care services to children and youth with cancer or serious hematologic disorder are eligible to become a full organizational member.
- Any Atlantic province individual concerned with the health care of children and youth with pediatric cancer or serious hematologic disorder, but who are not representatives of full organizational members are eligible to be individual members.
- Health centres where health care services are delivered to children and youth with cancer or serious hematologic disorder affiliate who do not wish full membership are eligible to be affiliate members.

There is no membership fee for individual members.

APPHON Coordinator: Terry March, 902-470-7429

Canadian Cancer Society Cancer Information Line

The Cancer Information Line provides clear, simple information about cancer – tailored to an individual's needs – including all types of cancer, prevention and early detection, treatment, side effects, clinical trials, complementary and alternative therapies, emotional and financial support, and services available in the community. The service is bilingual. In British Columbia, the service is also available in Mandarin and Cantonese on Tuesdays and Thursdays from 6:30 to 8:30pm.

The Information line can be reached at 1-888-939-3333 Monday to Friday 9am to 6pm.

Canadian Health Network

The Canadian Health Network (CHN) is a national, bilingual Internet-based health information service. Health Canada, its founding Partner, provides funding for CHN.

Through CHN, the Canadian public and health intermediaries alike can find excellent resources from health information providers across Canada. The CHN seeks to establish itself as Canadians' premier source of "health information you can trust."

CHN features 26 Health Centres focused on major health topics and population groups.

To date, there are links to more than 10,000 Internet-based resources on the CHN site. The CHN Subject Index includes over 1,000 terms pointing to information in these resources.

The site address is www.canadian-health-network.ca.

Canadian Breast Cancer Foundation-Atlantic Chapter

"Creating a future without breast cancer"

The Canadian Breast Cancer Foundation is the largest charitable organization in Canada dedicated exclusively to supporting the advancement of breast cancer research, education, diagnosis and treatment.

Funds raised by the Atlantic Chapter are returned to the provinces through the CBCF-Atlantic Chapter Pink Ribbon Research and Community Health Grants.

If you are interested in supporting or volunteering for the Atlantic Chapter, please contact our office or visit our web site at www.cbcf.org/atlantic

Nancy Margeson, Executive Director, toll free at 1-866-273-2223, or 902-422-5520